

## Transforming Your Care: Vision to Action

### A response from Participation and the Practice of Rights

Participation and the Practice of Rights (PPR) organisation provide tools and support to marginalised groups actively asserting their right to participate in economic and social decisions which affect their lives. Since 2006 we have worked to support mental health service users, carers and families bereaved through suicide in their work to improve mental health service delivery. It is on the basis of this work that we are contributing to this consultation.

The scale of the change proposed within Transforming Your Care is extensive – as such it is not possible for detailed analysis to be made of all aspects, rather PPR's response to this consultation offers main areas of concern which ought to be addressed before the Health and Social Care Board progress their plans any further. PPR intend also to make specific comments about the Transforming Your Care proposals regarding Mental Health Service delivery, an area which we have had specific involvement with through our support of the Belfast Mental Health Rights Group and the Card Before You Leave appointment card system.

#### Overarching concerns

##### **Privatisation**

PPR remain deeply concerned about any moves towards the privatisation of the health service in Northern Ireland. The role of government generally and the Health And Social Care Board, specifically, to respect, protect and fulfill the right to health is one underlined by international law. In particular, article 12, of the International Covenant on Economic, Social and Cultural Rights, to which the governments of the United Kingdom and Ireland are signatories, states;

*“The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”*

This obligation has been interpreted to include the provision that state parties must ensure that the provision of health services is free from discrimination<sup>1</sup>, of good quality<sup>2</sup> and economically accessible<sup>3</sup>. PPR are concerned that the current plans do not demonstrate appropriate cognisance of these obligations and are particularly alarmed that the public consultation document contains the following question;

“Question 5.

*Given the choice, who would you like to provide your care and support in your home?*

- 1. Statutory bodies*
- 2. Voluntary and community groups*
- 3. Independent sector*
- 4. A mixture of the above*
- 5. You would prefer to receive*

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<sup>1</sup> Committee for Economic Social and Cultural Rights, General Comment 14, paragraph 12 (b) (i)

<sup>2</sup> Ibid 12 (b) (d)

<sup>3</sup> Ibid 12 (b) (iv)

*the money yourself to choose*<sup>4</sup>

The obligations of the state in regards the right to health is a matter of international legal significance, not a choice to opt out of, it is therefore inappropriate for the Health and Social Care Board to consult on this issue.

## **Procurement**

Given the scale of the changes proposed, it is disappointing that no further meaningful detail is given about the HSC Board's plans to procure services. Indeed that there is insufficient foresight to examine the potential of a ten year plan when it is widely expected that the current economic recession will last for the rest of the decade, is disappointing. Linked to this, it also is a cause for worry that despite a main thrust of the proposals being to secure the transition of many services into a community based setting; no evidence is presented of there having been at least an independent audit of the capacity of existing service providers within the community to meet this. There is also insufficient detail on appropriate support mechanisms being established to ensure that both service providers and the staff involved will be supported to ensure that patient safety and clinical care standards do not suffer. PPR's experience of working in communities such as north and west Belfast would indicate that many of these community organisations are already overstretched and in need of additional support.

The HSC Board should also be mindful that their international human rights obligations and local equality obligations will not cease on the transfer of functions to third parties. It is disappointing that an acknowledgment of this is not articulated clearly in the strategy and PPR encourage the HSC Board to rectify this.

## **The rational for change:**

Whilst the document is at great pains to upfront any criticism that the need for change is being driven by cost considerations, it is unmistakable that change aligned with current and planned spending cuts has been at the forefront of the HSC's thinking in moving this strategy forward. In this context, any change must be viewed through the sharpened focus of how it protects the most vulnerable. PPR wish to put on record serious concerns that the change proposed here will be to the detriment of the clinical care necessary for the most vulnerable and wish to remind the HSC Board of the international human rights obligations in this regard;

*"Even in times of severe resources constraints whether caused by a process of adjustment, of economic recession, or by other factors the vulnerable members of society can and indeed must be protected by the adoption of relatively low-cost targeted programmes"*<sup>5</sup>

The legal translation of this obligation to protect the vulnerable in the Northern Ireland context is through the duty in Section 75(1) of the Northern Ireland Act 1998 to have due regard to the promotion of equality of opportunity across a number of named grounds and then equality screen and equality impact assess as appropriate.

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<sup>4</sup> DHSSPS (2012) "Transforming Your Care: Vision to Action – consultation document" page 13

<sup>5</sup> Committee for Economic Social and Cultural Rights, General Comment 3, paragraph 12

## Equality

PPR request that the decision taken by the Health and Social Care Board that an Equality Impact Assessment is not required for this strategy be reviewed. The main reason put forward for not conducting an EQIA despite 'major' impact being identified is that the plans are 'strategic' and that the 'detail of the implementation has yet to be worked out'.<sup>6</sup>

With reference to the current Guidelines for Public Authorities, the Equality Commission, states however, that;

*"Screening...should be completed at the earliest opportunity in the policy development process. For more detailed strategies or policies that are to be put in place, through a series of stages, a public authority should then consider screening at various times during implementation."*<sup>7</sup>

It continues;

*"To undertake screening after policy proposals have been developed may be inefficient in terms of time and may be ineffective if policy makers are reticent to make changes at a later stage."*<sup>8</sup>

PPR are also concerned that despite the broad evidence base being articulated in terms of inequality facing certain groups, the equality screening document does not sufficiently link this to the promotion of equality. It is not enough to identify the existence of an inequality, the law places public authorities under a positive duty to take action to promote equality of opportunity or tailor their policies to ensure inequality is tackled.

For example, whilst there is a welcome recognition that deprived communities suffer serious health inequalities across a number of indices in the Equality Screening document which states;

*"The 20% of most deprived areas in Northern Ireland represent nearly 340,000 people.*

*There is clear evidence of health inequalities in Northern Ireland, the consequences being poorer health outcomes observed in the most deprived areas than in the region generally such as:*

- lower life expectancy;*
- 33% higher rates of emergency admission to hospital;*
- 72% higher rates of respiratory mortality;*
- 59% higher incidence rates of lung cancer;*
- 82% higher rates of suicide;*
- self-harm admissions at more than twice the Northern Ireland average;*
- 55% higher rates of smoking related deaths; and*
- 124% higher rates of alcohol related deaths."<sup>9</sup>*

There is no meaningful discussion of the policy impact of this or of how the Health and Social Care Board will seek to ensure that through this strategy these inequalities are tackled. It is especially disappointing that evidence which does exist which would clearly

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<sup>6</sup> DHSSPS (2012) Transforming Your Care, Equality Screening Document, page 33

<sup>7</sup> P.51-52 ECNI Guidance

<sup>8</sup> P.52 ECNI Guidance

<sup>9</sup> DHSSPS (2012) Transforming Your Care, Equality Screening Document, page 28

contribute to ensuring that the HSC more appropriately paid due regard to the promotion of equality is ignored. In 2008, the Belfast Health and Social Care Trust, published research carried out by Mr Evan Bates entitled "A report on patterns and trends in the use of hospital services in Northern Ireland." This research analysed patterns and trends in the use of certain hospital services during the period 1998/1999 and 2006/2007, taking account of geographical area, age, gender and economic deprivation. It concluded that deprived communities disproportionately access health service through an A&E setting whereas their more affluent neighbours are more likely to access healthcare provision through GPs.<sup>10</sup> Had such evidence been considered more appropriately it is likely that the impact of moving care from a primary to a community setting would be viewed more accurately as having a probable disproportionate affect on deprived communities.

PPR are keen to underline the Health and Social Care Board's role, and the role of other statutory health providers, to design services around meeting the needs and rights of people instead of catering for the creation of a scenario which expects the reverse to happen. It is also worth noting, in this respect, that the international human rights obligations of the state in this regard, make the same conclusion. The United Nations Committee for the International Covenant on Economic Social and Cultural Rights have concluded the following;

*"States have a special obligation to provide those who do not have sufficient means with the necessary health insurance and health-care facilities, and to prevent any discrimination on internationally prohibited grounds in the provision of health care and health services, especially with respect to the core obligations of the right to health.*

*Inappropriate health resource allocation can lead to discrimination that may not be overt. For example, investments should not disproportionately favour expensive curative health services which are often accessible only to a small, privileged fraction of the population, rather than primary and preventive health care benefiting a far larger part of the population."*<sup>11</sup>

## **Governance**

PPR recognise that there is a need for change in health service provision in Northern Ireland; failings on the ground are evident and government statistics reflect this. However, it is important that such change, for it to be sustainable and capable of producing the right outcomes for the most vulnerable, follow a process and result in an outcome which is characterised by core values of transparency, accountability and participation.

PPR's work in the area of mental health has provided sharp insight into the failings of the current system with regards transparency and accountability. In the summer of last year, for example, PPR submitted a Freedom of Information request following the announcement by Minister Poots in April 2012 that special measures would be placed on the Belfast Trust and that 'accountability' meetings would be set up between the Department and Trust to monitor and improve the situation. This request was denied in August 2012 but when resubmitted in

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<sup>10</sup> Belfast Health and Social Care Trust (2008) "A report on patterns and trends in the use of hospital services in Northern Ireland."

<sup>11</sup> Committee for Economic Social and Cultural Rights, General Comment 14, paragraph 19

November 2012, both the Department and the Belfast Trust agreed to the request. Despite the statutory timeframe for responding having elapsed, however, both responses in their entirety are currently still outstanding.

Change must not happen in isolation of those who are directly affected by these proposals. Fundamentally, international human rights law recognises the following;

*“The formulation and implementation of national health strategies and plans of action should respect, inter alia, the principles of non-discrimination and people’s participation. In particular, the right of individuals and groups to participate in decision-making processes, which may affect their development, must be an integral component of any policy, programme or strategy developed to discharge governmental obligations under article 12. Promoting health must involve effective community action in setting priorities, making decisions, planning, implementing and evaluating strategies to achieve better health. Effective provision of health services can only be assured if people’s participation is secured by States.”<sup>12</sup>*

The experience of the Belfast Mental Health Rights Group and their work with the Health and Social Care Board, and Health and Social Care Trusts in the implementation of the Card Before You Leave appointment card scheme, has identified significant and internationally commended learning about how participation can be meaningful and capable of improving services. PPR encourage the Department to make use of this best practice example as they consider how to improve governance. More information about the Belfast Mental Health Rights Group and their work can be found at [www.pprproject.org/right-to-health](http://www.pprproject.org/right-to-health).

## **Mental Health**

PPR’s work with the Belfast Mental Health Rights Group has identified serious and systemic problems with mental health service design and delivery in Northern Ireland which has consistently failed the most vulnerable.

The Northern Ireland suicide rate increased by two-thirds from 1998-00 to reach 15.9 deaths per 100,000 population in 2008-10. The rate in the most deprived areas almost doubled in the same period to 29.0 suicides per 100,000 population. The gap increased from 60% to 80% higher in the most deprived areas. In 2008-10 the suicide rate in the most deprived areas was more than three times higher than in the least deprived areas. In North and West Belfast for example suicide rates now place the two areas 11<sup>th</sup> and 13<sup>th</sup> highest in the United Kingdom.<sup>13</sup> Last year 313 people lost their lives to suicide in Northern Ireland; this is the highest number on record.

Despite this the recent National Audit Office report clearly establishes that funding on healthcare per head, and as a percentage of public spending, is the *lowest in the UK*.<sup>14</sup> Also, health spending is falling at a far greater rate than in England despite ‘ring fencing’.

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<sup>12</sup> Committee for Economic Social and Cultural Rights, General Comment 14, paragraph 54

<sup>13</sup> A. Brock, A. Baker, C. Griffiths, G. Jackson, G. Fegan, and D. Marshall, “Suicide trends and geographical variations in the UK, 1991–2004,” *Health Statistics Quarterly* 31 (2006), p. 15. Available at [http://www.statistics.gov.uk/articles/hsg/HSQ31suicide\\_trends.pdf](http://www.statistics.gov.uk/articles/hsg/HSQ31suicide_trends.pdf)

<sup>14</sup> National Audit Office, *Healthcare across the UK: A comparison of the NHS in England, Scotland, Wales and Northern Ireland* Report By The Comptroller And Auditor General Hc 192session 2012–13 29 June 2012

Mental Health is 44% underfunded compared to England.<sup>15</sup> There appears to be little practical translation of the importance of this in the Transforming Your Care strategy.

PPR are concerned that this, in parallel with the failure to adequately assess how deprived communities, such as many of the communities in North and West Belfast, access mental health care provision will ensure that rather than targeting inequalities specifically with regard to suicide rates; this strategy will only serve to further entrench them.

It is also of serious concern that the refreshed Protect Life strategy is not given appropriate space within the broader context of strategies referred to within Transforming Your Care. Indeed, it would appear that a significant omission has been made in the Equality Screening document not to mention the key government strategy charged with tackling suicide. This is especially noticeable given that differing levels of suicide across Northern Ireland represent such a stark inequality.<sup>16</sup> Indeed, in a response to a Freedom of Information request in December 2012, the Department of Health indicated that no records exist as to whether the reduction of hospital beds as proposed in Transforming Your Care were factored into plans for the refreshed Protect Life Strategy. It is of deep concern that strategies of this scale and importance appear to pay so little regard to the approach of the other.

PPR have previously raised similar concerns around the impact of a reduction of hospital beds through the *'Excellence and Choice: A consultation on the Proposal to build an Acute Mental Health Inpatient Facility at Belfast City Hospital'* and in a letter to the Chief executive of the Belfast Trust in April 2010 in which we stated;

*"PPR is concerned that the manner in which this recommendation is being implemented by the Belfast Trust is leading to critical gaps in the services provided with potentially severe consequences. ...The need to ensure that appropriate community based services are in place in advance of a reduction in mental health beds is obvious..."*<sup>17</sup>

PPR wish to repeat such concerns again.

Disappointingly, further gaps in service provision are also evident within the Transforming Your Care Strategy. Children and Adolescent Mental Health Services (CAMHS) are mentioned with a view to the HSC Board's aim to continue to improve services. Specific reference is then made, however, to the recommendation to *"increase the availability of emergency CAMHS cover to avoid acute admissions."*<sup>18</sup> However, there is no further detail on this, and when this is read alongside the adult mental health recommendations which include to *"...develop 6 in-patient mental health units for those aged 18+ (emphasis added)"*<sup>19</sup> it is clear that there is a dangerous potential for children and young people to slip through the gaps and not receive inpatient care as medically appropriate.

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<sup>15</sup> Appleby, 'Rapid Review of Northern Ireland Health and Social Care Funding Needs and the productivity challenge: 2011/12 – 2014/15' [http://www.dhsspsni.gov.uk/final\\_appleby\\_report\\_25\\_march\\_2011.pdf](http://www.dhsspsni.gov.uk/final_appleby_report_25_march_2011.pdf)

<sup>16</sup> Page 10 of the Equality Screening document discusses other strategies in place. Whilst mentioning the previous Protect Life Strategy which expired in 2011, the current and refreshed strategy is not discussed.

<sup>17</sup> PPR correspondence to Mr McKee, Chief Executive, Belfast Trust, dated 12<sup>th</sup> April 2010

<sup>18</sup> DHSSPS (2012) "Transforming Your Care: Vision to Action – consultation document" page 45

<sup>19</sup> Ibid, page 36

PPR wish to underline the HSC Board's obligations to ensure that the most vulnerable are safeguarded and that plans are adequately resourced and include mechanisms to ensure that such divergences in treatment for adults and young people do not allow the vulnerable to fall through the cracks. It is also important to state that a full Equality Impact Assessment would be an appropriate mechanism through which to discover how the HSC Board's may appropriately discharge its equality duties with specific regards to the category of 'age'.

Finally, PPR wish to make specific reference to the recommendation regarding mental health carers and carers in general. Transforming Your Care makes the following recommendation;

*"Enhancing the support for carers to ensure that they have access to services in their community which enhance their quality of life."<sup>20</sup>*

Many of the carers who are members of or are involved more broadly in the work of the Belfast Mental Health Rights Group are providers of at-home care and are already under significant strain. It is unclear how Transforming Your Care can meaningfully ensure carers have adequate support if much of the statutory provision of respite care is being limited or withdrawn. The HSC Board must provide the evidence base for the recommendations issued here if they are to be translated into actions which benefit carers.

15 January 2013

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<sup>20</sup> Ibid, page 37